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The Barriers and Facilitators for Recognising Distress in People with Severe Dementia on General Hospital Wards.

Abstract

Introduction

Psychological symptoms and delirium are common, but under reported in people with dementia on general hospital wards. Unrecognised and untreated symptoms can manifest as distress. Identifying distress accurately therefore could act as a trigger for better investigation and treatment of underlying causes of it. The challenges faced by healthcare professionals to recognise and report distress are poorly understood.

Methods

We conducted 25 semi-structured interviews with a purposive sample of healthcare professionals working with older people in a general hospital. Interviews were transcribed and analysed generating themes that describe the facilitators and barriers of recognising and caring for distress in dementia.

Results

Regardless of training or experience all participants had a similar understanding of distress, and identified it as a term that is easily understood and communicated. All participants felt that the recognition of distress was something they could do innately. However the majority also believed it was facilitated by experience, being familiar with their patients, and listening to the concerns of the person's usual carers. Barriers to distress recognition included a busy ward environment, and some participants believed that others may lack the skill to identify distress in hypoactive patients.

Conclusion

Distress may be a simple and easily identified marker of unmet need in people with dementia on hospital wards. However, both modifiable and unmodifiable barriers are suggested that reduce the chance of distress being identified or acted on. Improving our understanding of how distress is identified in this environment, and in turn developing systems that overcome these barriers, may improve the accuracy with which distress is identified on hospital wards so that actions can be taken to reduce the suffering caused by it.

Introduction

Dementia is a common co-morbidity in older people admitted to general hospital [1]. Those with dementia in hospital often have difficulty orientating to their surroundings, communicating their needs and have a high prevalence of psychological symptoms (75%), pain (57%) and delirium (66%) [2-4]. This can cause discomfort resulting in distress [5]. Distress in this context is a broad umbrella term that describes any negative emotional state. At its extreme it can result in behavioural disturbance such as aggression, irritability, sleep disturbance and apathy [2, 6].

People with more severe dementia often struggle to communicate verbally. When this is the case it is believed that symptoms and distress are displayed through body language, vocal sounds and facial expression [7, 8].

One of the most widely accepted strategies to relieve distress in this group is to identify the distressed individual, establish the cause of distress and treat accordingly. Standardised symptom recognition tools exist to help healthcare professionals (HCPs) do this [9-11].However, such tools are often impractical and rarely used in hospitals in the United Kingdom (UK) [12, 13]. If distress is identified, algorithm driven management protocols, and targeted holistic or pharmacological treatment strategies exist to treat the causes [14, 15]. If distress or the causes of the distress are not identified, subsequent investigation and treatment may be suboptimal.

It has been reported that a discrepancy exists between documented and expected psychological symptoms, pain and delirium in people with dementia on general hospital wards [12, 16]. One explanation for this is that individual symptoms are difficult to recognise. To improve the diagnosis and management of individual symptoms, distress could potentially act as a sensitive trigger for further investigation downstream, if it were detected accurately [12]. Using distress in this way is similar to ‘track and trigger’ systems currently recommended for use in the UK, for example the National Early Warning Score for measuring physiological compromise [17] However, how distress in dementia is recognised and reported in this environment is poorly understood.

We aimed to explore how HCPs recognise and respond to distress in those with dementia on hospital wards, and the barriers that inhibit their ability to do so.

Methods

Design

A qualitative study using data collected via semi-structured interviews with HCPs who regularly care for patients with dementia on general hospital wards, analysed using thematic analysis.

Participants

Potential participants included registered nurses, clinical support workers, physiotherapists, consultant grade doctors and non-consultant grade doctors in permanent employment on four wards in a large teaching hospital in the UK. All wards cared for a high proportion of patients with comorbid dementia, and included orthopaedics, medicine for older people (acute and long stay wards), and a medical admissions unit. We used criterion purposive sampling, supported by a sampling frame, to represent a diverse range of opinions; variables included ward type, professional role and experience level, [18]. The minimum number of participants needed to satisfy the sampling frame was 17, however interviews continued until data saturation was achieved.

Recruitment

On each of the wards managers informed all staff about the study via a standardised email. The research team then contacted those who expressed an interest to participate, inviting them to interview. Some groups, particularly doctors, were more difficult to access in this way so snowball sampling was also used; asking existing participants to identify potential participants [19].

Data collection

Audio recorded semi-structured interviews were conducted in pre-booked meeting rooms at the participant's place of work. Outside interruptions and distractions were minimised [20]. Interviews were conducted by the first author (GC), a clinical lecturer in old age psychiatry. The interviewer had no established relationship with any participants prior to the interview. Before the interview participants received an information leaflet about the study, their rights and data protection. No repeat interviews were conducted.

In order that the data gathered were relevant, a topic guide was used. Questions were deliberately open and non-descriptive, allowing participants to convey their own understanding of distress, how it presents in a hospital setting, and the skills, systems and processes that make identifying and reacting to distress more or less difficult. Topics covered were generated following a literature review into the process of distress recognition in similar patient groups, and the topic guide was further refined iteratively, throughout the data collection period [7, 8].To stimulate further conversation, towards the end of the interview participants were presented with a table displaying the expected prevalence of psychological symptoms and delirium in people with dementia in a hospital setting [2, 4] alongside the frequency that these symptoms are actually reported in the medical record [12]. In most cases there was a large discrepancy between expected and observed symptoms. Participants were asked to comment on the challenges of recognising and reporting symptoms in this patient group.

Data analysis

Analysis and reflective practice occurred concurrently with data collection so emerging codes could enhance subsequent data collection. Interviews were transcribed verbatim, and checked for accuracy. Transcripts were not returned to participants for comment or correction. The computer based qualitative software programme NVIVO 10 was used to store, organise and assist in the analysis of the data.

We used thematic analysis to identify and report repeating patterns within the data, which formed the basis for themes. In order to approach the data systematically Braun and Clarks' 6 phases of thematic analysis were used as a framework [21].

Initial codes were inductive, derived from the data without a predefined construct or coding system, allowing for codes to be flexible and free form. The research questions guided areas of interest. To organise the codes into a manageable data set they were reviewed and collated where appropriate.

At regular intervals all codes were grouped by similarity to search for potential themes. This process was refined at each review, providing an opportunity to conceptualise the data in greater depth. From the final 5 transcripts no novel codes emerged, data were therefore coded directly into existing codes, and it was felt data saturation was achieved.

A number of measures was adopted to improve data validity and reliability. Reflective practice was used after each interview reviewing style, question structure and listening skills, being critical of biases, leading questions or any areas where information was not explored thoroughly.

Four initial interviews were coded independently by two analysts (GC and CB) in order to think of coding in as many ways as possible. The coding frameworks were then combined. Subsequent transcripts were coded by the first author (GC), with regular sense checks of the codes and themes with the co-authors (CB and MB).

At the end of analysis, an independent analyst performed a credibility check; a random sample of 40 previously coded quotes were placed into available codes. The percentage agreement was 76% with a Cohen's kappa of 0.75 indicating a substantial level of agreement.

Ethical approval was granted by the University of Leeds Research Ethics Committee, reference number SoMREC/14/094.

Results

Participants

Twenty-five participants from a range professional backgrounds, ward types, and experience levels were interviewed, Table 1. Interview duration ranged from between 19 and 42 minutes.

Table 1, The range of participants interviewed.

Participant characteristic	Number of participants
Medical speciality*	
Medicine for older people	11
General medicine	4
Orthopaedic surgery	11
Professional background	
Clinical support worker	5
Nurse	5
Physiotherapist	5
Junior doctor	5
Consultant grade doctor	5
Median years experience in speciality	5 (4-22)
Gender	
Female	20
Male	5

*Two participants worked in more than one speciality.

Results of the Thematic Analysis

Analysis of the transcripts produced four themes that describe how HCPs perceive distress, and the facilitators and barriers to recognising and acting on it. Figure 1 illustrates this in a theoretical model and demonstrates how the themes and codes fit together and relate to ward procedures. Themes are then described below using verbatim quotes, identified by the professional background of the participant, interview and line number.

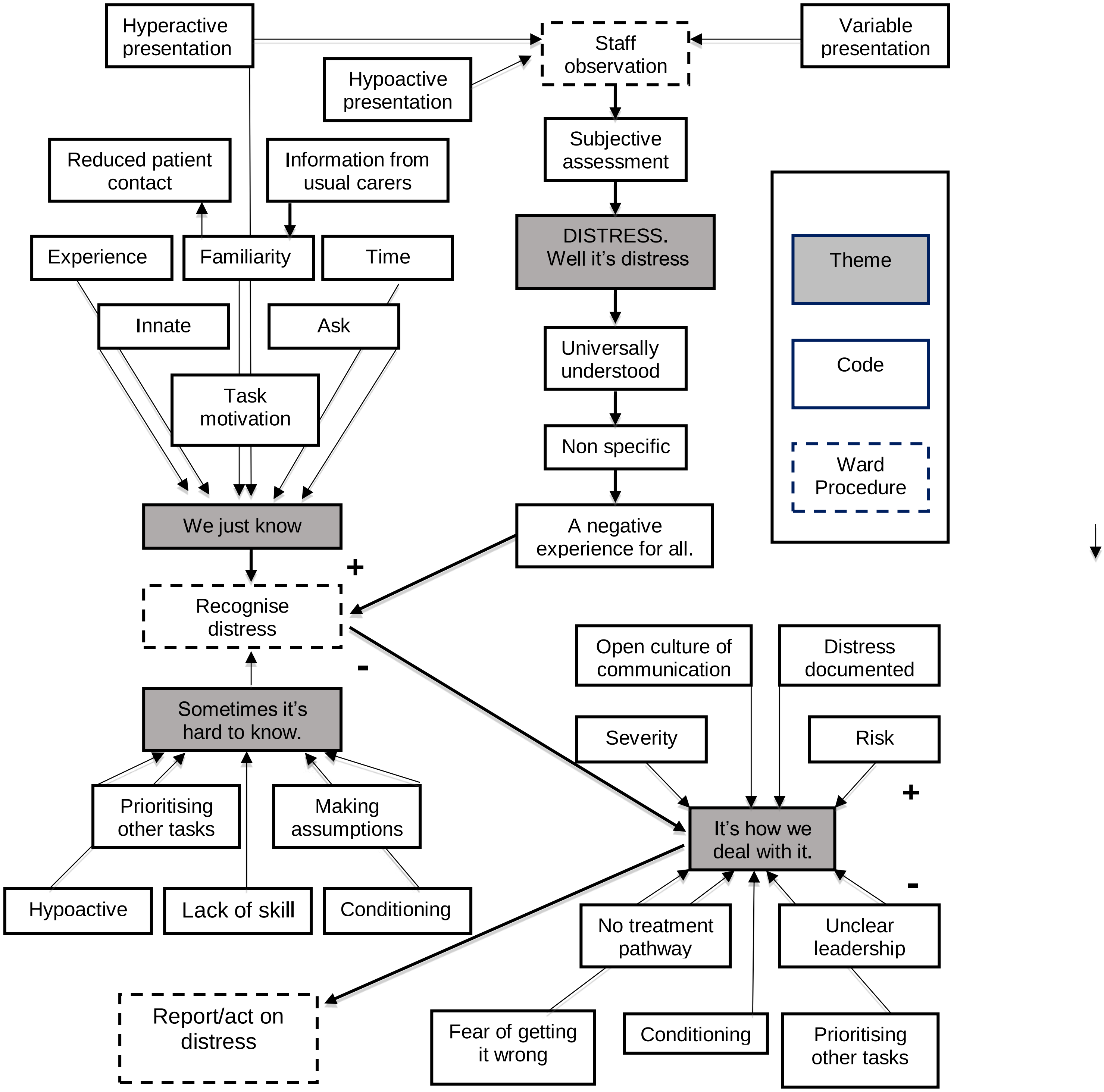

Figure 1, Theoretical model of the barriers and facilitators of distress recognition in dementia.

Description of themes

Theme: Distress is… well it's distress

"To me distress can mean a number of things. It could be an emotional response to something *that's going on around them, something internally happening with them or it could be a* distressed response to pain, environment or fear. *It's anything that's invoking in them a reaction that's* causing them harm." (Nurse, 13, 33).

Participants described that people with dementia in hospital who have a reduced capacity for communication, present in an "almost infinite", number of ways when distressed. Most participants described patients being verbally and physically active (hyperactive presentation). All but one participant then went on to describe scenarios where distressed individuals present quietly (hypoactive presentation). It was generally acknowledged that the signs observed were on a spectrum, temporarily variable and potentially changeable from one person to another. It was acknowledged that the type of presentation does not necessarily correlate to severity of suffering.

"[Distress] could manifest itself as really overt; crying, shouting, very tearful, maybe sometimes more agitated or looking uncomfortable. Sometimes I see people who actually are very withdrawn within themselves, and look fearful but very quiet." (Consultant grade doctor, 10, 30).

The majority of participants believed that all such descriptions fell under the broader *"umbrella"* term distress. All participants gave similar definitions of distress; a person's emotional or behavioural response to an external or internal negative stimulus. This was thought to be an advantage as it is easily usable by HCPs and lay people regardless of training or background. An identified downside however, is that distress is non-specific, and subjectively assessed.

All participants identified that distress was a negative experience for patients, HCPs, other ward residents and carers, which should be acknowledged and treated. Participants regularly stated that they often feel frustrated and helpless when faced with a distressed person, particularly if they perceive nothing can be done to alleviate it.

"I can only imagine and it must be horrible. It must be so frustrating for one. It must feel never-ending for them. It must feel that no matter what they say or do.. Because some of them can *say things but can*'t *verbalise exactly how they're feeling. They must feel so helpless."* (Clinical support worker 9, 277).

Theme: We just know

"You know what distress is. You just know what it is, so you can think 'right this patient's distressed'. I might not know what symptoms or signs they're showing, but I know they're distressed." (Nurse 8, 351).

Despite variability in presentation, every participant felt they were able to accurately distinguish a patient with dementia in distress from one who is not, by observing the presentations described above. Participants described this ability as natural or that they "just know". Exploring this concept in more detail participants often struggled to describe how they developed this skill, the majority believing it to be innate; a natural inclination to recognise those in need, motivated by a desire to care for a fellow human being. This skill was thought to be universal, transcending experience and training backgrounds, however participants recognised that they required empathy, motivation, pride in their work and enough flexibility to spend time with patients, to allow them to exercise it.

*“I don’t know what makes someone good at being able to tell if someone’s distresse*d, but I think if someone cares about their job, and cares about what they do, and cares about the *people they’re looking after, then those* qualitie*s…you know…you’r*e looking out for your *patients and you’re not just seeing to their physical needs*, *but you’*re going beyond that. So I *think anyone can identify someone who’s in distress, you just have to care and have the time*.*”* (Consultant grade doctor, 11, 100).

Having universally described the ability to recognise distress as natural, some participants were contradictory as to whether the skill could be enhanced with training and experience. Both experienced and inexperienced staff stated that the number of years spent caring for older people improved the ability to recognise distress, however, participants who had less clinical experience (<4 years) placed a greater emphasis on this.

A *“change in someone’s usual behaviour”* was a commonly described sign of distress. Participants acknowledged that familiarity with their patients’ usual behaviours helps provide a *“*baseline*”*. Facilitators to improve familiarity included; using a patient’s usual community carer as a source of information, minimising ward changes, reducing staff turnover, and maintaining high HCP to patient ratios.

*“*You get to know their norm. And a lot of the time, *if you’re unable to know their norm, family* and friends who come to visit will tell you what is, and what is not normal for them and then *you’ll have an id*ea of what to look for.*”* (Nurse, 20, 66).

Theme: Sometimes it is more difficult to know

No participant identified that they personally lacked motivation or ability to recognise distress, but some believed others may not be as skilled.

*“*I think some people are good [at recognising distress] an*d some people aren’t.* Some *people’s non-*verbals are so small, a sudden wince of a face, a difference in them, and not *everyone’s good at picking that up. A lot of people just say well yes she’s fine, she ate, she* drank, *she’s ok. And they just don’t see it, I don’t think that’s som*ething training can give you, an*d I don’t think that’s* experience, I think you either are able to see that *or you’re not.”* (Nurse 13,157)

Other barriers to distress recognition included low staff numbers, and HCPs prioritising *“*task orientate*d”*” jobs, or medically unwell patients. There was often a feeling of guilt associated with prioritising tasks ahead of distress recognition, despite the fact that in doing so they were following ward protocol.

“You know, you’ve come in to nursing to try and make the patients feel like a person, not a bed *number, not an inconvenience, but when staffing’s short you have to prioritise, regardless of* how hard that is. *We’re task orientated, washing, dressing, beds, whatever comes in the* afternoon, whereas it should be, meeting the needs of the patient as they arise, not when it suits us. But you have fifteen patients, *you’re just hoping* that no one gets too unwell. You *don’t have time to look if somebody’s tired, or even aggressive*.*”* (Nurse, 6, 215)

A hypoactive presentation was a commonly cited barrier to distress recognition. It was felt that unless the assessor was specifically looking for distress in this instance, it might not be identified. Finally it was identified that the complexity of dementia may at times influence HCPs ability or motivation to recognise distress or symptoms causing distress. Within this theme participants commonly identified that people with dementia are sometimes assumed to be in a chronic state of distress, and staff become conditioned to it, even if the presentation is hyperactive, or causing ward disruption. This can lead to an assumption that the patient does not require specific attention.

*"*I think quite often, particularly patients with dementia, people *see someone who's agitated,* who in our eyes is being disruptive, very loud, shouting out. And quite often people will say, *'they've got dementia, that's their behaviour', without stepping back and saying well actually is* this different to how they are normally? Is there something behind this behaviour?*"* (Junior doctor, 4, 71).

Theme: It's how we deal with it

*"*As a human being you can look at someone and you can tell that person is in distress, but how we all deal with it that is developed over time.*"* (Clinical support worker, 3, 216).

It was widely acknowledged by participants that recognising distress is only the first step of a process to reduce patient suffering. Commonly stated reactions to distress were; doing nothing (where distress is mild), escalating the concern to a more experienced HCP, documenting in the medical record or using a personal "checklist*"* to rule in or out causes of distress. Participants were unaware of any hospital based algorithms for treating distress in dementia, or standardised symptom recognition tools in common use. Determining when and how to act, was dependant on the person in distress, other ward priorities, and the ward culture and systems.

A hyperactive presentation was a commonly identified facilitator for positive action, particularly if the presentation was causing risk. As with distress recognition, participants identified that when distress is chronic, there can be a tendency to assume the behaviour is normal. This has the potential to increase the severity threshold at which distress is investigated or treated.

*"It depends what the patient's doing. If the patient's be*ing aggressive, hitting, punching, kicking, chucking their food all over, then obviously that is [going to be acted on], but if a *patient's just laid in bed, you wouldn't necessarily put 'patient appears withdrawn, not* verba*lising, not communicating'."* (Nurse, 6, 199).

As with distress recognition, prioritising distress reporting was dependant on other ward activities.

"So I think we're all kind of trained to recognise it, and relatively good at managing it, but I think sometimes people are very busy and they just want to get out of it what they need to *get out of it. And they're quite happy to* almost overlook the distress. Or maybe just pass it on to someone else to sort out.*"* (Nurse 25, 71).

When deciding whether to escalate patient concerns to a more senior colleague, participant responses varied dependant on training background and speciality. Junior doctors appeared the most reticent to refer on, fearing they may be seen to be *"*overreacti*ng"*, this was particularly evident in surgical specialities. Other barriers to open communication were a fear of technical language, or embarrassment at not knowing the cause of the distress.

On some wards, systems were in place to encourage HCPs to escalate concerns at daily safety briefings. These meetings attempt to change traditional hierarchical communication culture, welcoming the use of non-technical language. Participants felt they and their colleagues were able to escalate concerns more easily on wards that adopted this system.

"We try and make sure that on both the wards we're working on at the moment, at patient safety briefings in the morning, anyone can volunteer any worry they have about a patient. So it may be someone who is distressed in some way, or it may be something completely *different. We try and make that very open in the sense that 'look, has anyone just got a bad* feeling about anyone toda*y?', so anyone can volunteer anything."* (Consultant grade doctor, 10, 183)

Discussion

Principal findings

Distress was a universally recognised term among the participants interviewed, and describes a negative patient experience requiring action. Participants believed distress can be recognised innately, however the skill is enhanced by speaking to the patient, having dedicated time to observe the patient, staff motivation, the assessors level of clinical experience, familiarity with the patient, and listening to the opinion of their usual community carers.

Distress severity, and risk caused by it were believed to facilitate the reporting or investigation of distress, whereas a chronic or hypoactive state were perceived to be barriers. Participants believed that ward systems allowing open communication, and processes to document and treat it, encourage distress reporting.

The meaning of the results in the context of a clinical setting

Recognising and responding to distress requires HCPs to have a shared understanding of what distress is, the skill and time to recognise distress, and the systems in place to report and treat distress. The results have suggested both facilitators and barriers that if enhanced or overcome might have the potential to increase the proportion of people in distress who are correctly identified.

All participants had a similar understanding of distress regardless of training and experience. Some felt that the term was broad and simple, though all agreed that more complex alternatives, for instance identifying specific symptoms, were too complex for all HCPs. Using the broad umbrella term ‘distress’ as a way of identifying patients in need of further assistance, is likely to be sensitive but non-specific. The consequences of this are that some non-distressed patients could be investigated as if they were [22]. Any more specific, but less sensitive, descriptor would potentially leave patients suffering unnecessarily.

All participants seemed motivated to help people in distress, gaining intrinsic satisfaction from the task, and in doing a perceived “good job” [23]. The over-riding feeling however was a sense of hopelessness and frustration about not having the time to recognise distress, or knowing how to help their patients in the face of what is often a complex clinical scenario. Changing ward culture to give parity of esteem between emotional and physical discomfort, and allowing HCPs the time and encouragement to recognise distress could potentially improve this [24].

All participants believed they possessed the necessary interpersonal skills to be able to recognise distress innately. This supports existing theory on assessing distress, in those who cannot communicate verbally [25]. The reliability of this has not been tested however, and is a potential area for further work.

It might be assumed that a HCP’s experience and training in dementia care would further enhance innate skill. No evidence for this exists, and participant responses were often contradictory about the benefit of training on a skill which they had previously identified as innate. In those who felt training might benefit their ability to recognise distress, the response almost always felt disingenuous. Demonstrating the effect of experience and dementia training on a HCP’s ability to recognise distress is a potential area for further work.

Modifiable facilitators to distress recognition included; increasing familiarity with the patient, and dedicating HCP time to distress recognition. Being familiar with a patient allows a healthcare professional to understand the patient’s behaviours, and so be more responsive to a change. Familiarity will be enhanced by the amount of time the patient spends on the ward and consistent staff provision. Patients may benefit therefore by reducing the number ward changes during an admission, and having named HCPs as key workers, though this can be challenging with 12hour nursing work shift patterns. It must also be considered that familiarity could also have the converse effect: HCPs becoming conditioned to distressed behaviour, and less sensitive to subtle changes.

A further way of enhancing familiarity is to seek advice from the person with dementia's usual community carer. Patient and family centred care approaches are recommended in the United Kingdom and have delivered positive outcomes in other specialities, particularly paediatrics [26] . Encouraging family members to contribute to the distress recognition process, could improve the accuracy with which distress is identified.

Participants described consciously prioritising other ward tasks ahead of acknowledging those in distress. This may at times be entirely valid; hospital wards are often busy environments, and staffing levels can fall below recommended operating levels [27], so affording time to 'non-essential' tasks may be difficult. A potential way of overcoming this would be to make the observation of distress a routine task, similar to measurement of physical observations [17].

Participants consistently stated that they were unaware of systems or treatment algorithms to help people with dementia in distress. Causes can be varied, so treatment options downstream and their individual efficacies are extremely varied. However evidence based treatment algorithms to help clinicians investigate and treat complex symptoms in dementia exist and their use is widely accepted as good clinical practice [14]. Increasing HCP's awareness of the existing systems for investigating and treating patients in distress may have potential to improve patient care.

The open communication of information between professionals without fear of judgement can improve patient safety [28]. Some participants, particularly junior staff or those in surgical specialities, felt worried about communicating a belief someone was in distress to senior colleagues, fearful of being wrong, or causing unnecessary bother. This view was not shared by more senior or experienced participants. Finding a language for the communication of distress that transcends training and experience might increase the likelihood of open communication. Such an intervention would require a significant change in hospital culture. Similar heuristic approaches have been suggested for managing complex symptoms in patients at the end of life in dementia. It is argued that by using simple, understandable 'rules of thumb', assessment processes are still sensitive, but quicker, transparent and less complex [29].

Strengths

The HCPs interviewed all cared for people who have dementia, providing first-hand accounts. Participants were also from a range of specialties and professional backgrounds with varied levels of experience.

To improve reliability data was initially coded by more than one analyst and credibility checking with an independent coder demonstrated a substantial level of agreement.

Limitations

All participants worked in the same hospital, which limits transferability to other settings.

HCPs from five different professional backgrounds were interviewed. These groups were selected, following consultation with the host wards, as their roles regularly include symptom and distress recognition. Other clinical HPCs such as occupational therapists and speech and language therapists were not interviewed, and represent a potential missed source of data, however it is not believed that their inclusion would have significantly altered the results.

Participants were a self-selecting group. It is likely that they had an interest in the subject or wanted their views to be known. This has the potential to create biased and polarised results.

On hospital wards when staffing levels are low, external agencies are used to provide temporary staff. No temporary staff were interviewed as they are not employed by the hospital trust included in the study. This creates a potential missed source of data.

Every interview was conducted by a clinician that specialises in dementia care (GC) and participants were aware of this. This creates the potential for assumed knowledge to inhibit a thorough exploration of opinions, and can influence the interviewer / interviewee dynamic by preconceived ideas about job role and career seniority [30]. These risks were mitigated as far as possible by regularly reviewing interview style, and practising reflexivity.

Conclusions

The study findings suggest that distress may be a simple and easily identified marker of unmet need in people with dementia on hospital wards. However both modifiable and unmodifiable barriers exist that reduce the chance of distress being identified or acted on. It is hypothesised that encouraging HCPs to use innate distress recognition as part of standard hospital procedure may be an effective way to trigger appropriate investigation of the causes of the distress downstream. This has the potential to allow patients with dementia in hospital better access to appropriate and timely care.

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